

“Our Commitment To The Disabled Child”
Presented to the Conference on Improving Services to Handicapped Children
Through State/Local Collaboration
Washington, DC
June 2, 1983

This meeting was sponsored by Georgetown University Child Development Center and its Department of Pediatrics, The Health Resources and Services Administration, and particularly its Bureau of Health Care Delivery and Assistance in the Division of Maternal and Child Health, and the Division of Personnel Preparation, Special Education Programs, Office of Special Education and Rehabilitative Services of the Department of Education.

Notable other speakers were Philip L. Calcagno, MD, Chairman, Department of Pediatrics at Georgetown, Ed Sontag, Ed.D. Director, Special Education, U. S. Department of Education, and Madeline Will, Acting Assistant Secretary, Office of Special Education and Rehabilitation Services, Department of Education.

I seized the opportunity at this meeting to talk about the “Baby Doe Regulations”, which had just been published by the Department of Health and Human Services, and although, because of the stage of the Legislative/Regulative process I could not speak in detail on this subject. I did use this opportunity to mention the uniqueness of every human life and that the major global problem was hesitation in nation by nation to commit sufficient resources to the saving of every life that it has. Stilling walking a tightrope, I used the opportunity to bring his life-long experience on dealing with both “Baby Doe’s” (newborns afflicted by a congenital anomaly incompatible with life, but nevertheless amenable to surgical correction) and the subject at hand.

I then turned his attention to the substance of the meeting citing barriers to cooperation as well as those things which encourage it, stressing need for attitudinal training, the difference between voicing hopelessness, and offering false hope to confuse and frighten parents, the strengthening of social services personnel, the need for great familiarity with the available resources at any given community, and finally, something that would be a hallmark of my time in Washington, and that is the age old problem of community and state services being organized according to the perceptions and convenience of the people who provide the service, rather than of those who need it.

I closed with observations on technology, in neonatology, and in the collaborative planning in medical, education, and social services.

“Baby Doe” Regulations
Congenital anomalies
Control of technology
Cost of saving a human life
Disabled infant

Infant & child health in USA

Infant mortality

Neonatal dilemmas

Research of disabled children

Respirator dependent child

Role of parents

Sanctity of life

Department of Education

Department of Health & Human
Services